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ACQUIRED IMMUNODEFICIENCY  
SYNDROME:  
ETHICAL AND PSYCHOSOCIAL  
CONSIDERATIONS

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**I**N the preface to a recently-published monograph on the acquired immunodeficiency syndrome (AIDS), the editors characterize this disease as one of the most fascinating and potentially devastating communicable diseases of history.<sup>1</sup> Within four years of its initial description in 1981,<sup>2</sup> the causative viral agent of AIDS was described nearly simultaneously and independently by American scientists led by Dr. Robert Gallo at the National Cancer Institute and by French scientists led by Dr. Luc Montagnier at the Pasteur Institute in Paris.

The present essay focuses on some of the ethical, psychosocial, and public policy issues related to AIDS. Only one<sup>3</sup> of numerous monographs on AIDS<sup>1, 4-8</sup> has a chapter devoted to the ethical and psychosocial issues in AIDS.

## THE AIDS HYSTERIA

Public hysteria in response to the AIDS epidemic has been, in part, fueled by the mass media and the nation's newspapers and magazines. Sensational headlines such as "AIDS: A Time Bomb", "Nurses Quit Jobs, Won't Treat AIDS", "AIDS Panic Disrupts American Blood Banks", "Fear of AIDS Curbs Sex", "AIDS-Fatal Mystery Disease", "The AIDS Hysteria", "AIDS Patients Victimized Twice: By Disease and Public's Fears", "AIDS—Can the Nation Cope?", are not at all uncommon in the lay press or in medical publications.

Many examples of this public hysteria can be cited. There are "morticians who refuse to embalm AIDS victims, street sweepers who demand face masks before cleaning in homosexual neighborhoods, AIDS patients evicted from their homes, dismissed from a jury," and prohibited from attending school. Blood banks suffer from a lack of donors who stay away in droves mistakenly believing that one can contract the disease by giving blood. Patients who need blood transfusions refuse to accept blood of strangers and demand to provide their own donors. Physicians and other health workers are refusing hepatitis B vaccine for fear of contracting AIDS. One California congressman proposed legislation which would shut down public bathhouses, ban young AIDS victims from school, make it a felony for a person in an AIDS high-risk group to donate blood, forbid discrimination against nurses who use protective garments in treating AIDS victims, and prohibit a person with AIDS from practicing in the health care industry.

The American Hospital Association published a feature article on AIDS entitled "AIDS: A time bomb at hospital's door",<sup>9</sup> and depicted a time bomb with a lit fuse in graphic color on the cover of the January 5, 1986 issue of its official journal, *Hospitals*. The Association, in an attempt to defuse the fear and panic its own article may have engendered, issued guidelines to hospital personnel who treat AIDS patients. The American Hospital Association feels that the real AIDS epidemic may be one of fear, and strongly endorses education as a forum for attacking fear. AIDS hysteria is being overcome by public education, community responsiveness, political activity by the homosexual community, and a more visible role by AIDS experts.

## THE PHYSICIAN'S RESPONSIBILITY TO CARE FOR AIDS PATIENTS

Medical history and tradition are replete with examples of physicians whose devotion to their patients transcended any possible personal danger of contracting their patients' disease. Physicians caring for patients with plague,

cholera, typhoid and polio occasionally became victims themselves. Yet, throughout the ages the physician's obligations not only to his patients but to society, the health professionals, and to himself have been clearly accepted as axiomatic. The American Medical Association's "Principles of Medical Ethics" clearly states<sup>10</sup> that "a physician shall be dedicated to providing competent medical service with compassion and respect for human dignity."

Nevertheless, some anesthesiologists have been reluctant to give anesthesia to AIDS patients, some surgeons have tried to avoid doing lung biopsies to document *Pneumocystis carinii* infections, and some pathologists have shunned performing autopsies. The legal and ethical proprieties of the case of a gastroenterologist who refused to endoscope an AIDS patient with gastrointestinal bleeding are openly discussed in a prestigious medical journal.<sup>11</sup> In caring for AIDS patients, one must weigh the physician's risk against his responsibility. According to a prominent medical ethicist, "taking risks requires courage, and facing a danger that is direct and threatening is the highest test of courage."<sup>12</sup> Physician ignorance and physician homophobia may be relevant here. There is now convincing scientific evidence that the danger to health workers or household members caring for AIDS patients, however, is exceptionally low.<sup>13,14</sup>

Hospitals, too, have neither the legal nor moral right to refuse admission of AIDS patients if these hospitals can provide diagnosis and treatment. How should a hospital or medical staff respond when a care-giver refuses to care for an AIDS patient? What measures might be effective (e.g., counseling and educating) and which measures may be counterproductive (e.g. disciplinary action)?

#### THE COST OF AIDS TREATMENT AND RESEARCH

The Centers for Disease Control in Atlanta estimates that the national cost per day for an AIDS patient is \$830, twice the average daily cost for treating other patients. Some of the reasons for this high cost include intensive nursing care, high costs of drugs (especially antibiotics), and supplies (bed-side and laboratory), frequent use of specialized diagnostic equipment and procedures, and lack of adequate long-term care arrangements after discharge. This figure of \$830 per day translates into a \$1.25 billion bill for treating the first 9,000 AIDS patients. With the number of AIDS patients doubling every 10 to 12 months, the impact on hospitals whose daily reimbursement per patient is \$400 or even \$500 could be devastating without adequate planning. Many large hospitals lose more than \$300 per day on each AIDS patient. Hospitals are grappling not only with the increased cost, much

of it not reimbursed, of caring for AIDS patients, but also on how much to allocate and reallocate their personnel and other than personnel services to the care of AIDS patients.

Projections about the cost of AIDS, however, are based on data of questionable reliability. Changes in the mix of patients between intravenous drug users and homosexuals and changes in the treatment (a trend to shorter inpatient stays is becoming apparent) will dramatically affect estimates of cost. Patients with intravenous drug use are more expensive to care for because they often lack social, financial, and material support. Total cost of AIDS care, even at the highest projections, will still be less than 1% of the cost of all illnesses in 1990. Thus, some of the concern about the cost of caring for AIDS patients may be exaggerated. Moreover, there is significant regional variation in the cost of care. For instance, in San Francisco the extensive availability of community and volunteer resources has resulted in an average cost per patient that is only one fifth the national average. Several projects are underway to stimulate such community involvement in other cities.

State and federal help toward the economic burden of AIDS on our health care system was slow in materializing. Although budget allocations have dragged, federal spending for AIDS has increased dramatically during the past three years. The Public Health Service estimated that it spent \$108.9 million on AIDS in fiscal 1985 compared with \$61.5 million in fiscal 1984 by diverting funds from other programs. Despite mounting evidence that the disease is spreading, the administration sought only slightly more than the previous year's \$70 million budget request for AIDS treatment and research in fiscal 1986. Nevertheless, the administration later heeded the recommendation of the Public Health Service and increased its 1986 budget request to \$126.3 million.

On a state level, belated commitments and fiscal support of AIDS services are beginning to become visible. In January 1986 the New York State Hospital Review and Planning Council adopted emergency measures to amend the health code to designate centers for the care of AIDS patients. The intent of the regulations is to increase access to essential services with emphasis on the use of home care and community-based support services through individual patients care management, and comprehensive discharge planning services for AIDS patients. Designated AIDS centers will receive a higher reimbursement rate to provide AIDS patients coordinated and comprehensive services and programs, including inpatient, outpatient, and post-hospital nonacute services.

The designation of AIDS centers committed to enable AIDS patients to

maintain the quality of their lives in a home environment as long as possible will be beneficial for hospitals, individuals with AIDS, and their families. The AIDS centers concept is based on a continuum-of-care model designed to meet and/or arrange for all levels of care and needed services required by AIDS patients, including ambulatory and inpatient services, home health care, and personal care services, psychosocial and psychiatric services, arrangement for needed housing, legal and financial assistance, and, as appropriate, hospice services and residential health care services.

Other states with large numbers of AIDS patients such as California, Texas, Florida, and New Jersey are initiating major efforts similar to those undertaken in New York. To date, inadequate resources have been directed toward home care for AIDS patients after discharge from the hospital. Such patients lie in acute care hospital beds long after they are eligible for discharge because they have no place to go. In New York one homosexual activist said that he can place nonacute AIDS patients in first-class hotel rooms and provide around-the-clock nursing care for the same price that the city pays to keep those patients in hospital. In Chicago a community group estimates that local AIDS patients could use a communal residence but there isn't one.<sup>15</sup>

Three ethical issues related to AIDS as well as other serious illnesses include the ethics of clinical trials, the apportionment of costs of clinical research, and the availability of experimental drugs.<sup>16</sup> As experimental treatment for AIDS becomes available, pressure is increasing for double-blinded placebo-controlled clinical trials. Investigators and/or patients may resist because of reluctance to use a placebo for a fatal disease. AIDS patients are young, often well educated, and unwilling to rely solely on physicians' recommendations, perhaps because the recommendations are not worth much since AIDS patients eventually die of their disease. The cost of clinical research is part of the overall problem of the allocation of financial resources to the overall effort to treat and eradicate AIDS. Who should pay for experimental therapy? What happens if third party payers refuse to pay for experimental therapy when no standard therapy exists? Certainly patients with AIDS deserve equal access to high quality medical care, including experimental therapy, no less than cancer patients.

#### ETHICAL ISSUES IN BLOOD SCREENING FOR HIV

Although AIDS occurs primarily among promiscuous homosexual men and intravenous drug users, it also afflicts hemophiliacs and others who become infected by contaminated blood products. To protect the nation's blood

product recipients from the risk of acquiring AIDS, a crash program was undertaken in the United States to develop a screening test for HIV. On March 2, 1985 the Food and Drug Administration approved the first of five applications from pharmaceutical companies to market a blood-test kit to detect antibody to HIV. The test has very high sensitivity and specificity, meaning that only a very rare false positive or false negative result may occur. Some initial concerns expressed<sup>17</sup> included that the test had not been adequately evaluated and that the results were imprecise, that confidentiality of results could not be maintained and that the disclosure that an individual had a positive test result could lead to discrimination against that person, and that the test result might be used inappropriately for diagnostic or even nonmedical purposes.

Although panic-provoking headlines such as "AIDS contaminates world's blood,"<sup>18</sup> "The unacceptable face of blood banks,"<sup>19</sup> and "A new Pandora's box: HTLV-III tests"<sup>20</sup> are rarely seen anymore, many of the ethical concerns have not abated. There still is fear that a registry of donors whose blood has the AIDS antibody will leak out and homosexuals and drug abusers will be discriminated against in employment, health insurance, and housing.

People at high risk of developing AIDS have and continue to be urged not to give blood. But what about those "healthy" people who have a positive test? How should they be notified? What should they be told? What does a repeatedly positive test mean for the donor? According to Centers for Disease Control recommendations,<sup>21</sup> such a donor should be questioned about possible exposure to the virus or risk factors for AIDS. Additional laboratory studies might include tests for sexually transmitted diseases, for immune function, and where available for the presence of HIV virus in body tissues. One group of experts<sup>22</sup> speculated about the total cost of this medical evaluation and who is responsible for it: donor, blood center, or blood recipients. These experts also point out that it is difficult to determine conclusively whether a person is infected with HIV by his life style or history alone. Questions have also been raised about discrimination, insurability, and employability of persons identified as antibody-positive. Testing for antibodies in the sera of the patients' sexual partners may be useful, a suggestion strongly criticized by some interested parties. Thus, there are substantial social and psychological implications for donors who are informed that their blood sample is reactive for HIV antibody. These issues are confounded by the lack of information regarding the prognostic implications of a true positive test.

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### CONFIDENTIALITY, PRIVACY, AND TRUTH TELLING

When the test kits were introduced, the Food and Drug Administration mandated notification of antibody-positive donors, whether or not they wished to be informed. Two bioethicists point out<sup>17</sup> that normally people have a right not to know the results of medical tests; however, when the public health is involved there are precedents for mandatory notification. The American Red Cross and the New York Blood Center notify only donors with a confirmed positive test but maintain a local registry of those found positive on a single test and discard their subsequent donations, all without their knowledge. Because of the psychological and social burdens associated with notification, the issues of mass screening and reportability should be approached very carefully.

The availability and introduction of the test to screen blood for HIV antibody stimulated the launching by the National Heart, Lung and Blood Institute in Bethesda of an epidemiologic study of antibody positive blood donors found among 200,000 healthy volunteer blood donors. Two of the ethical concerns of this study<sup>23</sup> are whether or not the donors should be told later that their blood was found to be positive or negative for HIV, and whether or not recipients of blood products should be traced and told that the blood they received was contaminated.

The Centers for Disease Control, through state and local health departments, collects demographic data on the incidence and manifestations of AIDS. Formal surveillance of seropositive persons or those suspected of having early AIDS or high risk groups is part of ongoing research projects in several high incidence areas. Other studies of currently healthy homosexual men to follow the natural history of AIDS and behavioral changes among high risk group people, health care workers, blood donors and recipients, hemophiliacs, and others are also in progress. Charges of breach of confidentiality against the Center for Disease Control have led it to develop a coding system for reports on patients with AIDS.<sup>24</sup> Society must figure out how best to draw the line between privacy and the right to know. Surveillance by its nature is invasion of privacy and its possible outcomes potentially invade certain other civil rights. The most threatening scenarios include the use of inappropriate or broadly imposed quarantine, the recriminalization of homosexual sexuality, or the inappropriate restriction of employment, access to housing, or other restrictions on the civil rights of persons in at-risk groups.<sup>25</sup>

### DECISIONS TO TERMINATE TREATMENT

The stress on both physician and patients with AIDS is markedly accentuated when decisions have to be made regarding termination of treatment. A vivid case illustration entitled "If I have AIDS, then let me die"<sup>26</sup> concerns a 28-year-old homosexual man with AIDS who was hospitalized for a first episode of *Pneumocystis carinii* pneumonia and who refused to have a Swan-Ganz catheter inserted in his pulmonary artery and requested that medical treatment be stopped. The medical team discussed in detail with the patient, his lover, and his parents and sister his clinical status and prognosis: the patient had, they believed, a 50% chance of surviving the current illness. However, people with AIDS rarely survive more than two years, and the patient could expect several bouts of severe illness during his remaining lifespan. They also pointed out that rapid advances were being made in understanding the pathophysiology of AIDS and offered the prospect for a future treatment as a result of current research efforts. The patient had no psychiatric history and had never attempted suicide. He did not want to commit suicide but wanted to be allowed to die. In the presence of witnesses, he signed a living will refusing further treatment. What should be done? How should the medical staff handle this situation? Should treatment be stopped?

One argument is that just as a person under physical or psychological duress cannot give informed consent, neither can a person under physical or psychological duress give informed refusal. Therefore, the medical staff should procrastinate the implementation of the stop-treatment request and allow the patient to recover from his sense of hopelessness and despair, to guide and comfort him through the fear and discomfort of invasive procedures.

Another approach is to assert that this patient is a competent, rational adult and cannot be subjected to invasive medical procedures without his consent. This is a basic right in American law. Decisions made by an informed, competent adult must be respected. A third approach is to accept the fact that, under certain circumstances, choosing death can be a rational decision that should be honored but the criteria by which an individual can be judged sufficiently competent to make such a momentous decision are not clear. Thus, if the patient's resolve is tested and remains steadfast after reasonable efforts to convince him otherwise, his choice of no treatment should be honored.

Preferences of other homosexual men with AIDS for life-sustaining treatment were recently surveyed in a study of 118 male patients<sup>27</sup> which concluded that most patients with this fatal progressive illness have thought about



life-sustaining treatment, have preferences about their care, and want to discuss life-sustaining treatment with their physicians. However, many patients have not provided advance directives, including some who might benefit from the durable power of attorney for health care. Many patients also have misconceptions about the effectiveness of life-sustaining treatment, even though they are well educated and live in a city where their illness is widely publicized. Some AIDS patients become mentally incompetent and unable to participate in decisions. Homosexual men may want their lover or a friend to make decisions for them but the latter cannot do so unless he is legally designated. Patients who want aggressive therapy, including life-sustaining treatments, should receive it unless the prospect of success is virtually nil. Patients who want supportive care should be reassured that caregivers will provide this care and not abandon them. Physicians should clarify the patient's wishes about life-sustaining treatment when the patient is competent and should encourage patients to provide advance directives.

#### EMOTIONAL REACTIONS OF PATIENTS, FAMILIES, AND CAREGIVERS

Patients with AIDS may fear disfigurement, debilitation, infection, and death, as well as social abandonment involving isolation not only from society and work colleagues, but from relatives, close friends, and lovers. Patients with AIDS may also suffer from guilt and remorse over past sexual behavior patterns, low self esteem, worthlessness, and anticipatory grief as well as social withdrawal and isolation.<sup>28</sup> Maintenance of employment, limitations of support networks, and difficulty in obtaining insurance are major problems for AIDS patients. Other special problems for many AIDS patients include minimal or nonexistent contact with their families of origin, living alone, and vulnerability to psychological dysfunction sometimes related to cerebral involvement by the disease.<sup>29</sup> The psychological and social impact of AIDS may result in psychiatric symptoms similar to those seen in other life-threatening diseases, including anxiety, depression, and delirium. It is difficult in the early stages of AIDS to separate reactive depression and psychomotor retardation from symptoms associated with central nervous system complications of the disease.<sup>30</sup>

Families of patients with AIDS are also under severe psychological stress. They fear acquiring AIDS from the patient. They fear stigmatization by society by being related to a homosexual. They may recently have discovered the homosexuality or drug addiction of their relative and have difficulty coping with the possibility of the person's death. Major family conflicts may arise about the patient's lifestyle and especially with the patient's lover or

friend who may have more influence on the patient than the family. After the patient's death, the family may have feelings of guilt and self recrimination.

The enormous demands placed upon the time, effort, and energies of physicians, nurses, social workers, and other caregivers place considerable emotional stress upon these health professionals. Physicians and other providers also suffer considerable frustration and psychic distress related to the intractability of the disease, the failure of many treatment efforts, the often fatal outcome, the lack of cooperation and compliance of many of the patients, and the reluctance of some coworkers to serve these patients.<sup>28</sup> The emotional and physical toll on medical residents in municipal hospitals has increased because of the large number of AIDS patients cared for.<sup>31</sup>

#### SUMMARY

The acquired immunodeficiency syndrome (AIDS) has been described as this century's greatest health peril. Thousands have already died from the disease and there is no cure in sight. The medical, epidemiologic, viral, and immunologic features have been well described and the causative virus identified. Attempts at prevention of the disease by developing a vaccine, screening of all blood, organ and semen donors, and educating high risk groups to change or avoid behavioral risks have been slow, in part because of underfunding and legal issues of constitutional rights. The emotional toll on patients with AIDS, their families, and their caregivers needs to be actively and aggressively addressed. Public hysteria should be alleviated by a well planned, coordinated, and implemented educational program involving not only health professionals but the mass media and press, which have in part fueled the public fear about AIDS. Prudent practices in the health care and private industry workplaces have been suggested and should be followed. Governmental involvement in terms of increased AIDS treatment and research funding is sorely needed and seems to be forthcoming. Public policy decisions need to be made with compassion, understanding, and the conviction that this disease may eventually be overcome by a concerted effort of all parties concerned.

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